

AD _____

Award Number: DAMD17-99-1-9107

TITLE: Latina Breast Cancer Patients and Their Informal Support
System

PRINCIPAL INVESTIGATOR: David E. Hayes-Bautista, Ph.D.

CONTRACTING ORGANIZATION: University of California, Los Angeles
Los Angeles, California 90095-1406

REPORT DATE: September 2000

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

20010327 055

REPORT DOCUMENTATION PAGE			Form Approved OMB No. 074-0188	
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503				
1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE September 2000		3. REPORT TYPE AND DATES COVERED Annual (1 Sep 99 - 31 Aug 00)
4. TITLE AND SUBTITLE Latina Breast Cancer Patients and Their Informal Support System			5. FUNDING NUMBERS DAMD17-99-1-9107	
6. AUTHOR(S) David E. Hayes-Bautista, Ph.D.				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of California, Los Angeles Los Angeles, California 90095-1406 E-MAIL: dhayesb@ucla.edu			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited				12b. DISTRIBUTION CODE
13. ABSTRACT (Maximum 200 Words) <p>Purpose. To understand the influence of Latino culture in breast cancer treatment, by developing a conceptual model of the informal support system utilized by 60 triads consisting of Latina cancer patients, their spouses/significant others and family/friends. Participants are drawn from the Breast Cancer Treatment fund, which provides payment for services for uninsured women.</p> <p>Findings. The project has allowed a view into the role and function of the psycho-social support system. Not only does the support "team" assist with the diagnosis, treatment and consequences of breast cancer, it also helps the patient "connect the dots" of a disjointed system by negotiating, supplementing and extending services. Another key area of finding is that the supporting the spouse/partner has been neglected by the medical world. The loss of a breast does not seem to be as significant as the potential loss of a person key in creating a family.</p> <p>Significance. A better understanding of how the psychosocial team functions to assist the patient in "connecting the dots" allows an understanding of where and how the services system does not reach into this population. Programs and policy at the individual and system level can emanate from the emerging conceptual model.</p>				
14. SUBJECT TERMS Breast Cancer			15. NUMBER OF PAGES 27	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

Table of Contents

Cover.....	1
SF 298.....	2
Table of Contents.....	3
Introduction.....	4
Body.....	4
Key Research Accomplishments.....	26
Reportable Outcomes.....	26
Conclusions.....	26-27
References.....	27
Appendices.....	27

(4) INTRODUCTION

The purpose of this research project is to understand the influence of Latino culture in breast cancer treatment, by developing a conceptual model of the informal support system utilized by 60 triads consisting of Latina cancer patients, their spouses/significant others and family/friends. Participants are recruited from the Breast Cancer Treatment Fund program, which covers the cost of treatment for uninsured women with breast cancer. Four types of triads are being interviewed; 15 rural immigrant; 15 US born rural; 15 urban immigrant; 15 US born urban. Open-ended interviews with an interview guide, rather than a standardized closed-ended questionnaire, is used in order to allow the triads to describe their social interaction in the face of a diagnosis of breast cancer. Topics probed in the interview guide include: familial responsibilities; information obtained regarding breast cancer detection and treatment; patterns of discussion and conversation regarding the diagnosis; experiences with control or lack of control; experiences with fear or lack of fear; experiences with health care providers. The interviews are conducted bilingually to preserve the code-switching that naturally occurs. Interviews are being analyzed via a Grounded theory process, which provides for identification and conceptualization of patterns in the responses of participants. These will lead to a conceptual model of the Latina breast cancer experience, and can serve as a basis for program development in education and formal support group development appropriate for a Latino population base.

(5) BODY: Research Accomplishments for Each Task

Task 1: Finalize recruitment plan. Months 0-4

As required by human subjects regulations, and as a result of identifying legal barriers presented by the Breast Cancer Treatment Fund, the recruitment plan and protocol for outside staff (UCLA) recruitment were finalized prior to project start date. Staff roles within the Breast Cancer Treatment Fund were restructured to allow their staff to make the first contact with subjects. Only when a woman granted verbal permission for contact with a UCLA nurse did that contact occur.

Task 2: Finalize initial interview guide. Months 4-6

The initial interview guide was finalized prior to project start date as a requirement of human subject compliance regulations.

Task 3: Identify and recruit sixty (60) Latina women diagnosed with breast cancer, their male partner and a friend and/or other supportive relative. Months 6-28

Recruitment Of Study Participants

In the early months of the project, each step of the research process was discussed with the staff of the Breast Cancer Treatment Fund. It was felt that time spent in such discussion would help create an effective research team.

Staff followed the protocol for identifying, recruiting and interviewing Latina women described in the approved Human Subjects application to UCLA's Office for the Protection of Subjects and described in the approved IRB application to the Dept. of Army's IIRB committee. The UCLA research nurse (interviewer) would act upon the referral from the Breast Cancer Treatment fund quickly—within two weeks—to build on the interest created in the subject by the Breast Cancer Treatment Fund research team of nurse Lisa Gordon and health educator Guillermina Garcia.

However, recruitment of study participants got off to a slow start. The first woman was identified and interviewed in November; in December, a change of staffing and the holidays interrupted the research process, delaying the process until January.

Task 4: Interview sixty (60) Latina women diagnosed with breast cancer, their male partner and a friend and/or other supportive relative. Months 6-30
--

Twenty seven triads have been interviewed—a total of 81 interviews have been completed. Among them there were fifteen rural immigrant triads, seven urban immigrant triads, five rural US- born triads and one urban US-born triads.

Scheduling the interview

At times, it was difficult to honor scheduling requests made by participants. Not only do participants have to find an interview time they consider workable given doctor appointments, work and family commitments, but they seem to need time to reflect upon the request and “mull” it over.

In year 1, we found that after the interviewer made the first telephone contact, participants needed time to discuss the purpose of the research in detail. To find that “best time,” the interviewer always makes it a priority to be flexible in her work and personal time. For many participants, “the best time” for the kind of lengthy discussion they needed was either in the evening or on a Saturday. Occasionally, appointments were cancelled, even as little as one hour before the scheduled time of arrival.

Informed Consent

The approved consent form, available in English and Spanish, is three pages long. Most of the participants have not been comfortable reading documents this size, and have needed anywhere from 20 to 45 minutes to complete the informed consent process.

Many times, the interviewer was asked to read the consent form out loud. Family members also helped read the consent form for the participant. To date, only one

participant said she had previously participated in a university-based research project. Participants would frequently ask why the U.S. Army Medical Research and Materiel Command would fund a research project on breast cancer in Latinas; responding to their curiosity stimulated much interest in the project and served to warm up the brief "interviewee-participant" relationship.

The success of this initial interviewee-participant conversation is critical. The research nurse will run into difficulties if the participant does not feel comfortable, feels confused or suspects that the purpose of the research is other than what has been explained to them. In order to create the greatest possible rapport between the participant and the interviewer, only the UCLA project nurse calls upon the participant to discuss the research and to schedule the interview after the first contact has been made by the Breast Cancer Treatment Fund Research Team. The interviewer takes as much time as necessary to hear concerns, answer questions, and inspire confidence.

So far, all participants have been willing to share their experience and many have requested a follow-up contact to learn what the final analysis revealed.

Travel to Interview

The challenge of interviewing women living in rural areas and of completing each leg of the triad is the time and mileage involved. 9,825 miles have been logged interviewer's car. When it is possible to schedule interviews back to back in the same general location, the interviewer will spend the evening at a low cost hotel. Each interview is emotionally exhausting and beyond the actual time of the interview time is spent building rapport and reading the consent form out loud. While the most productive days has yielded 3 interviews within a 10 mile radio of each other, these days are rare, the usual is 1-2 interview per location day.

Place of Interview

In all but two instances, the interviews have occurred in the participant's home. In one of the two exceptions, the interview occurred in the interviewer's car while the participant was on a lunch break from McDonald's. Another participant needed to be interviewed outside her small apartment as family members were sleeping.

Length of the Interview

The average interview lasts 90 minutes, though some have lasted 120 minutes and two were less than 90 minutes long. The length may vary because the interviewer conducts the interview in a manner which allows participants to tell their story.

The process of interviewing

The interviewer actively listens to the story as it unfolds, and probes as necessary. Some participants have said that they "hold" the questions from the informed consent form in their mind as they discuss their experiences. At times, if the interview process feels "too natural" or "emotionally satisfying"; they may suspect that the questions on the consent form have not been covered. Some will even pull out the consent form, point to the

numbered paragraph with the questions and check to see that they did in fact answer all the questions in the consent form. All research questions are always covered during the interview.

Bringing Closure to the Interview

After the interview the intimacy created as a result of the interview is respected. Participants feel comfortable asking the interviewer, who is representing not only the study but UCLA and the Dept. of the Army, many questions about higher education, breast cancer treatments, English as a Second Language classes, reconstructive surgery, to read English written letters, advice about husbands, advice about grown children etc. Some participants offer the interviewer crochet articles, others have offered bags of carrots, red onions and recipes. When the interview is done often the interviewer is introduced to the young adult children, neighbors, and extended family members.

Task 5: Analyze data. Months 10-33

Transcription of taped interviews

Each interview takes about 1 ½ to 2 hours. A 90-minute tape takes approximately 16 hours of staff time to transcribe and produces a document of about 60-120 pages in length. Though very time-consuming, transcription of each taped interview is critical to the analysis. We have had to rely on other sources of funding to hire the staff needed to assist with the transcription of interviews. Transcribers must be fluent in Spanish as well as English and be able to translate easily from English to Spanish and from Spanish to English. Patience is a virtue, many participants speak; softly, with undulating voices, some voices are heavy with regional accents, while others are rapid and very breathy. The transcriber must back up and hear again the conversation until it is familiar enough to capture.

The Analysis

Cell #1: Rural Immigrant Women (a total of 15 women have been interviewed)

- The women's ages range from 41 to 66, with a mean of 51.3
- The staging of cancer: one woman was diagnosed stage IV; two women were diagnosed at stage III; nine women were diagnosed at Stage II and one woman was diagnosed with cancer DCIS (ductal carcinoma in situ)
- Fourteen women were interviewed in Spanish and one was interviewed in Spanish and English.
- Rural Immigrant Women represent the rural communities of Livingston, Planada, Harvard, Fresno, Merced, Arvin, Tipton, Hughson, Westley, London, Orange Cove, Fresno, Lamont, Modesto and Indio.

- All women but one suggested having worked in agricultural fields as laborers at some time in their life.
- With the exception of one individual, none of the women in the rural immigrant cell had a high school education.

Cell #2: Urban Immigrant Women (a total of 7 women have been interviewed)

- The women's age range from 26 to 51.
- The staging of cancer: one woman was diagnosed stage III; four women were diagnosed stage II and for two women, the stage of cancer was not obtained.
- Of the seven urban immigrants interviewed, most mentioned their high school education.
- All seven women, with one exception, were married and have children.
- Urban Immigrant Women represent the communities of Santa Ana, Visalia, Ontario, Highland, San Bernardino, Riverside, and Fontana.

Cell #3: Rural US-born Women (a total of 5 women have been interviewed)

- The women's age range from 49 to 61 years of age.
- The staging of cancer: three women diagnosed stage II; two women diagnosed stage I.
- Rural US-born Women represent the communities of Delhi, Tipton, Handford, and Fresno.
- All women are married and have children.

Cell #4: Urban US-born Women (only 1 woman has been interviewed)

Emergent Conceptual Categories All the interviews completed to date (81 individuals interviewed, representing 28 triads) have undergone an "open-coding" analysis, a first level of analysis which seeks out themes embedded in the reported experiences as read in the transcriptions. While over half of the triads remain to be interviewed as of this report date, some initial themes have emerged.

The following is a brief summary of major themes that have emerged to date. These data have not yet been published, and should be treated as preliminary, and not for general public distribution yet.

THE SOCIAL-SUPPORT "TEAM"

Participants described relying on their support systems in a number of ways for their interactions with the medical care system.

Providing A Social Worker. In all immigrant rural households, the support systems included family members who had lived in the United States all their adult lives and spoke English comfortably. They ranged from US-born daughters-in-law to US-born adult grandchildren. This family "language and systems" coordinator was able to interact with bureaucracies, complete paper work and be resourceful. Enjoying an important place in the extended family, these individuals, usually women experienced with the health care system, have translated for many family members and are consulted about every detail. They help judge the sincerity of the doctor and help weigh the treatments suggested.

"Y mi hija le hizo una cita aquí en la clínica" BC6

And my daughter made her an appointment here in the clinic. BC6

"A ella le debo mi vida por que ella fue la interesada, para que a mi me hicieran todo esto. Ella fue la que apuro por mi, ella fue la que me decia vente, vente nana, vente... y como le digo, me vine y por eso...me pego un dolor ya operada" BC6

To her I owe my life because she was the one who seemed to care, so that I would have all this done for me. She is the one who worried about me, she was the one who would tell me, come, come nana, come... and like I was telling you, I came and because of this... once operated I felt a pain. BC6

Providing Ears. Spanish-dominant women as well as English-dominant women utilized their support team to help them understand the information being imparted to them. As one women expressed it so eloquently, she needed her team to "be my ears." In these cases, the social support teams were assembled and were relied upon to reply to what was said during the doctor's visit. Besides replaying the doctor's announcement of the diagnosis, these psychosocial support teams were reported to be involved in everything from examining the initial lump to translating treatment details.

"Let's hear what the doctor says. I'm going to make an appointment on Friday to talk to us. With what he can do. But I'm going to go, you're going to go with me. I'll call my comadre (my child's godmother) and tell her. She's very intelligent. She knows a lot. I felt that I can trust her. To be my ears that I can't hear because I can hear, but I don't hear. I can hear everything but it's so much to handle that I am hearing so much that I'm hearing almost nothing at all". BC4

Providing Presence. Latinas in this project, similar to Latinos in other projects we have done, reported their support system providing presence while they dealt with the cancer. Being alone was described as something to be avoided, and the support team helped provide that presence.

"Siempre me acompañan, ellos o el otro hijo....Yo nunca me he sentido sola"

They always go with me, them or the other son... I have never felt alone.

"...y ahora con mas gana, hasta la comida hay veces me llevaba allá. Y luego no quiere que me quede en la cama, andale vamonos pa alla. Y es no le gusta que yo este alla en mi cuarto sola acostada. Siempre tengo que estar aquí en la sala, donde el me puede estar mirando"BC12

...now even more, he used to take me food all the way over there. He doesn't want me to stay on bed for too long, he takes me out. He doesn't want me to stay by myself laying on my bed. I always have to be in the living room with him, where he can see me. BC12

Providing Psycho-Social Support. An important job described for the support team was to be the designated "cheerleader" responsible for motivating their women to keep on. Members of a woman's family helped her fight sadness. A supportive individual was one who cheered the woman on. Many different Spanish phrases were used to express the cheerleader role that "supportive" individuals took on:

"Si, pues si tengo mucha familia...No pues que...dice usted no...por que a veces me veían así, decían "Ud. no se mortifique, todo esto va a salir bien, todo nos va a salir poco a poco." Siempre así tratándome de sentir animada y todo" BC11

Yes, I have a lot of family... No well... you say... because sometimes they would see me like that, and would say "Don't mortify yourself, everything will be fine, everything will come little by little." Always like that, trying to make me feel hopeful and everything. BC11

"Échale ganas"
give it your all

"Este... una si, y una no, por que todavía no me sentia bien cuando ya iba a recibir la quimioterapia entonces yo decía, ¡no! No puede ser, no me siento bien para ir a la otra quimioterapia, entonces se enojaban los niños, "¡mami! Tienes que ir" y el niño "andale mami, no te hagas tonta, ve, ve y es por tu bien" ¡pero no podía, no podía!.." BC21

Um... one yes, and one no, because I still didn't feel well when I went to receive the chemotherapy, and then I would say, no!, It can't be, I don't feel well enough to go to chemotherapy once again, and then the children would get upset, "Mom!, you have to go", and my son would say "come on mom, don't be dumb, you must go, go, it's for your own good!" but I couldn't I couldn't"...BC21

Believing, The one element that demonstrated hope and determination to overcome cancer was faith, expressed in many ways. Generally, the patient first accepted her cancer and then worked hard to conquer it through positive thinking.

"Es que hay que darle duro a la vida y, y tener fe uno. Que si uno tiene fe en el de arriba, y si uno... uno lucha contra eso, uno sale adelante". BC 16

You have to work very hard to succeed, and have faith. If you have faith, the one up there (God) and then you fight against that (cancer), you will succeed. BC 16

The power of the mind over the physical body was described repeatedly. References were frequently made to the power that a healthy positive mind has over an ailing physical body. Often, these rural immigrant women described a will to live that seemed to be strengthened by repeated difficult times.

Failure to serve their family was feared by many. Some women would describe the burden they felt they would become, not so much because they might require assistance but because their diagnosis would bring anxiety or worry to family members.

"...yo nomás le pido a Dios... creyentes, católicos, verdad? pero yo le pido a Dios mucho de que pues tanto a el, como a mis hijos....todos estuvimos en un curso. Allí estaban las mujeres, y allá los hombres. Tres días estuvimos encerrados...la iglesia católica somos cursillistas" BC9

I only ask God... believers, Catholics, and I ask God for him (partner) and for my children that... we all attended a church's retreat. Women and men were separated. We were three days locked up... of the catholic church we are members. BC9

"Yo pidiéndole a Dios, prendiendo velitas a que no fuera ser, verdad?, cáncer" BC 16

I lit candles and asked God make this not true, that it not be cancer. BC16

"Si... esto es mucho, esto es mucho por lo que esta pasando uno aquí, todo el tiempo esta pensando, pensando que estas enferma...¡nomás pensando! En ves de quedarte este...en ves de pensar tanto, voltearte a otra cosa, hacer otra cosa. O si estas, piensa y piensa en lo mismo, mejor ¡ve, salte!, salirte a platicar o salirte con tus amigas, o salirte para fuera. O algo! Pero nomas no estar pensando en lo mismo, en eso" BC6

Yes...this is a lot, it's a lot what one is thinking here, always thinking, thinking that you're ill... just thinking. Instead of staying um... instead of thinking so much, turn to another thing, do another thing. Or if you're thinking and thinking of the same thing, go outside instead, outside to talk or go out with your friends, or go outside. Or something! But just no thinking of the same thing, of that. BC6

Expanding Social Support

An Emerging Circle of Affected Woman Women reported of having a friend, or knowing other woman in the area, who had been diagnosed with breast cancer. In one small agricultural town, it was alarming to them to learn that breast cancer had been diagnosed in several women and had claimed the lives of two. Cancer was described as a topic of conversation among those who had been affected.

Creating Paths of Awareness for Others A group of women found that they were sought out for advice and education by others who wanted to know more about their experience with cancer. Some women gave testimony at their religious gatherings, others stood up and gave testimony at migrant farmworking town meetings. The difficulty of explaining a diagnosis of breast cancer in a young (usually less than 40 year old) woman was described by one participant:

"Uy...yo conozco mucha gente aquí y en mi tierra también. Y a esa muchacha vive cerquitas de un pariente. Y le platico lo que me había pasado, y ella fue personal al preguntarme y eso, como usted me esta entrevistando a mí. Me entrevisto a mí. Entonces ella vino a Tucson, y está joven la muchacha, pero dicen que no esta bien. Me platicó mi pariente que no esta bien, que esta bien triste" BC6

Ooh... I know many people here and in my homeland. And that lady lives close to a relative. And she told her what had happened to me, and she went personally to ask me, just like you're interviewing me. She interviewed me. Then she came to Tucson, and the lady is young, but they say she is not fine. My relatives told me she is not fine, that she is really sad. BC6

In the small rural town of Wesley, where farmworkers live on government labor camps between October and May, a child-care center is one informal source of education for immigrant farmworking women. As part of migrant education, in-service training is provided to parents on child development research. Participants with such experience expressed the need to provide a similar in-service on topics related to women's health. As

a result of participating in this research experience, one participant described her desire to ask the school coordinator to include breast cancer in future in-services.

"Ah, en veces este...tenemos training. Entrenamientos que son antes de empezar a trabajar. Pero casi son mas de, de niños...Estaba pensando eso yo, eso es lo que yo estaba pensando, pues sería una buena idea también que nos dieran, también algo para nosotros, verdad? Una información también para nosotros...Por que agarran personas, este para que hablen diferentes temas. Y yo pienso que así...digo que sí se enfocaran en algo que quisieran...así. Ellos buscaran una doctora, un doctor, o alguna enfermera, o alguien que nos hablara de, de lo que quisiéramos información" BC6

Because they get different people, um so they can speak on different topics. And I think that like that... I mean if they focused on something they wanted... like that. They looked for a female or male doctor, or a nurse, or something so they would talk to us about, about information we wanted. BC 6

...Marzo fui a una conferencia a Los Angeles de programa de inmigrante.....Muchos no sabían, pero yo me pare y les dije "que no se dejaran que yo estaba sufriendo del cáncer pero que ya estaba mejor...y no dejaran de ir a un doctor a hacerse un chequeo, que no tuvieran miedo, que hay muchas agencias que ayudan, por que a mi si me han ayudado mucho, que yo no he pagado nada y si les hablé un poquito de lo que estaba sufriendo y pues yo creo que si entendieron...BC21

... March I went to a conference in Los Angeles by an immigrant program... Many didn't know, but I stood up and said, "to not give up, that I was suffering from cancer but I was now better... and to not stop going to a doctor to get a check-up, to not be scared, that there are many agencies who would help, because they have helped me a lot, that I haven't paid anything and I did talk to them a little on what how I was suffering, and well I think they understood... BC21

PREOCCUPATION WITH FAMILY

During the interviews, women shared their concerns about their children. Often the conversation flow changed topics to the respondents' children (both adult children and younger children at home): advice about a child who wasn't doing well in school, a son who was going through a divorce or a young adult daughter unhappy in her job. Despite their lack of English or their lack of information regarding health care systems (and their dependency on others for this type of assistance), the women felt the responsibility to care for others as a clearly defined and never forgotten task. It was not unusual for a lengthy discussion of family concerns to come after the interview. One woman who shared many of her family concerns during the interview felt her family was now okay since her son's wife returned to him after hearing about the breast cancer operation.

"...Ya les arregle papeles, ya, ya todos están bien. ..No mas el que esta con esta muchacha, estaba solito en esos días. ...ella vino y se junto con el..Entonces le digo ya estoy contenta...Ya hice todo estoy contenta. Si me muero, que ya están todos bien aquí. Que les preocupa, les dije" BC 19

"...I fixed all their papers, everybody have their documents now...Only, this girl's husband doesn't has legal documents...she came, and moved in with him. I'm happy, I did what I could, I'm happy. If I died, everyone one is ok now. There is nothing to worry about...I told them" BC19

Patient-Husband Relations

Some themes have emerged from the description of experiences between patients and their husbands.

Intimacy Husbands of women diagnosed with cancer pitched in and helped with household chores, keeping appointments being present during most, if not all, the stages of treatment. The difference appeared to be in how much they wanted to learn about the details of treatment. Husbands reported needing to keep busy. A few husbands shared the fear they felt at the thought losing their wife to cancer. Much sadness was observed—many husbands cried during the interview.

Most of the participants we have interviewed are uninsured and immigrant, and the husbands feel responsible for a certain amount of frustration. As one participant later said, “We are poor, I don’t speak English—there is so little I can do for her.”

When husbands felt they could not bear to see their wives’ mastectomy scars, this attitude was interpreted by the interviewer as arising not so much disgust but from a feeling of failure on their part to protect the mother of their children from harm. The following accounts are examples from the women’s point of view.

“Este pues, yo le dije “quieres verme la herida?” dice, “mira tu, y despues dime” y se fue ya que le dije, “no pues quedo bien” yo me vi “quedo bien” le digo, “ahora tu” BC5

Well I told them, “Do you want to see my operation.”, [he] said, “you look”, and then tell me, and he left (the room) once I told him it turned out good, “its good, now you look”. BC5

“Aprendió a hacer unas sopitas huevonas. Sopitas huevonas son las de Top Roman. Add the water, ya hierve el agua El se portó muy bien ese día. That day, the rest of the day...BC4

He learned to make lazy soups. Lazy soups are Top Ramen. Add the water, then the water boils. He was very good. That day, the rest of the day...BC4

One particular incident that remains imprinted on the mind of the interviewer is that of an older woman who comments after the interview as she is showing her crochet tablecloths that her husband’s penis had been “burned” because they didn’t tell her how soon after chemotherapy she and he could have intercourse. She ran next door to ask her daughter in-law for advice, it was decided to rub vaseline on the penis. A call was made to the doctors and the effects of chemotherapy was explained

The Missing Breast If a breast was removed, the prosthesis was cherished. Women generally only had one prosthesis, and some had been worn and washed repeatedly and were in dire need of repair. One woman took out this valuable possession and demonstrated to the interviewer how she had carefully repaired it with yards of cellophane tape.

“ No, eso no se lava mas que, la pura telita, la de arriba. Este es silocona... pues, y se rompió todo el plastiquito de lo delgadito que esta” BC 6

No, that is not to be washed, just the little cloth, the one on top. This is silicone... the plastic got torn because the top material is very fine. BC6

For some men it was difficult to see the scar. One woman found courage and an opportunity after her interview to express to her husband her feelings of rejection.

"...And my husband too, he has not even seen my scar, because he does not want to see my scar. He does not want to see it because he wants to remember me how I was. You think it doesn't hurt?...he wants to remember me the way I was, complete. In other words he is saying I'm not complete. At least that's how I'm getting it...I mean he is good. He jokes around with me now that have any hair ...but its not the same" BC 8

Floundering Husbands. A few husbands felt clumsy and didn't know what to do to help their wife. Some were reported as being, only able to say, "Don't miss any appointments. Others found they needed to keep their wives active. None of the women reported their husbands requesting emotional direction from their physician. None reported their husbands receiving emotional support. They inferred that their husbands seemed at a loss.

"...me hicieron los tratamientos de quimioterapia, luego fueron las radiaciones, y luego otra vez la quimioterapia y como le digo fue muy duro para mí! El apoyo de mis hijos fue muy importante para mí, el de su papá no tanto, pues el nomás me decía "pues ve con el doctor, no falles" y yo hubiera querido que él haya estado conmigo para apoyarme, pero no se pudo...mis amigas, mi amiga y su hija, eran las que me daban a veces el raite a veces no...el apoyo de mi amiga en Los Ángeles fue también muy importante ella me decía "no se deje, no se deje" BC21
...they conducted the chemotherapy treatments on me, then came the radiations, and then chemotherapy again and like I've told you, it was really hard on me! My children's support was extremely important for me, the one of their father not so much, since he would only say "well go to the doctor, don't miss" and I would have liked him to be with me to support me, but it didn't work out... my friends, my friend and her daughter, were the ones who would sometimes give me a ride, not all the time... the support of my friend in Los Angeles was also really important, she would tell me "don't give up, don't give up" BC21

COMMUNICATION

For Spanish-dominant women, the very fact of communication was difficult. As few providers were ever described as speaking Spanish, the language issue loomed large in the interaction, and the role of the social support team in solving the problem was described.

Feeling marginal. For monolingual Spanish-speaking women, feelings of being marginal were expressed many times. The unfortunate tendency by some medical providers to speak in a loud voice when the patient does not understand their language has the effect of alienating the patient, who may interpret such loudness as scolding.

"Me da sentimiento, a veces que si me gritan así o algo, y que me griten recio. Me da mucho sentimiento" BC6

It gives me grief, sometimes they yell at me, or something like that, and when they yell loud. It gives me much grief. BC6

Non-Verbal Language. Some described studying the facial expressions of their health care providers for information they could not get verbally, because of the communication lack.

"I said, you don't need to tell me. I can see it in your eyes"

Interpreters. Spanish dominant respondents described the difficult process of having their interactions with the doctor take place via an interpreter.

"...entonces mi amiga me dice "creo que el doctor te esta diciendo que tienes cancer" le dije "no, no se! No le entiendo!..pero yo tengo que investigar! Ya entonces mandó llamar a una señora para que me interpretara, ya entonces la señora me dijo "Sabes que? Te esta diciendo que tú tienes cancer en el pecho" H, no me hubiera dicho eso! Porque me puse..este, este jextremadamente mal, muy mal!" BC20

... and then my friend says, " I think the doctor is telling you that you have cancer" I said, "I, I don't know! I don't understand him!... but I have to investigate! The doctor then had a woman called so that she would interpret me, and then the lady told me, "You know what? He is telling you that you have cancer in your breast" Oh, she shouldn't have told me that! Because I got... um, um extremely sick, really sick!. BC20

Many questions went unanswered by women, who felt that partial explanations were given by those doing the translating. Women described suspecting their interpreters, whether family members, friends, or an employee of the doctor or clinic, of not translating verbatim what was said.

Participants described a desire to have translators repeat what was said, and wanted to hear details of what was still not completely understood, before they would feel that the communication was complete. These women seemed to desire their translators to be emotionally supportive, and able to surmise what was not easily understood by the woman they translated for. The responsibility for satisfactory communication was put on the translator, as she or he was assumed to be in control of the interaction.

Communication Held Hostage A lack of expertise in communicating by medical personnel was described, and sadly accepted, by many women who did not want to jeopardize their care by "antagonizing" the doctor who held their future.

" No pues yo, yo seguia con mi duda de que pues, que me habian operado, y yo tenía, todavía residuos que me habian dejado. Por que yo antes, yo antes les preguntaba y les preguntaba y no, nadie daba razón ni el doctor ni nada cuando me quitaban puntadas y todo, y el doctor que a mi me opero nunca quiso decirnos, nada. Hasta ese doctor que tuvimos un cita, que me dijo que...."BC 6

No well I continued with my doubt, that although I had been operated, I still had residue that had been left inside of me. Before, I would ask them, but no one would give me a reason, not even the doctor, no one. Not even when they would remove parts of my breast. In fact the doctor that used to operate on me, never wanted to tell us. BC 6

Prior negative experiences with the medical world create insecurity and distrust in many patients. Knowing a little about the patient's previous experience with the world of

medicine could help facilitate communication and improve the patient-physician relationship.

"Yo le pregunte al doctor "que por que antes, no se les decía a los pacientes que tenían cáncer?" "por que antes no teníamos las facilidades de curar el cáncer. Ahora si podemos" cuando mi hermana tenia cáncer, no quiso que le dijéramos y murió de cáncer. El doctor decia que se le deciamos se iba a morir mas pronto. Yo pienso que es mejor que no lo engañen a uno. De principio duele que le digan a uno la verdad, uno no quisiera, pero es mejor la verdad. Dios me mando esta enfermedad y tambien me ayuda a superarla. El doctor me esta haciendo todo eso, pero yo me siento normal." BC11

I asked the doctor, "Why didn't you tell the patients that they had cancer before?" Why didn't we have the facilities to cure cancer. Today we can. When my sister had cancer she did not want us to tell her and she died of cancer. The doctor said if we would have told her, she would have died quicker. I think it is better not to deceive anyone. In the beginning it hurts to tell one the truth, we don't want to, but the truth is better. God gave me this sickness and also will help me suppress it. The doctor is doing all that to me, but I feel normal. BC11

Good Communication Skills With A Dash of Humor When a good relationship was developed between a monolingual Spanish-speaking woman and a monolingual English-speaking doctor, the details of the interactions were described affectionately.

"Muy bien, muy bien" me dice palabras dice en Español....A veces dice gracias, thank you, gracias...y le digo ¿o ya esta aprendiendo español? y nomas se rie. Pero así, así, es muy amable. BC11

"Very Good, very good", he says words in Spanish...Sometimes thank you he says, thank you, thank you...I tell him "Are you learning Spanish?" all he does is laugh, but like that, just like that, he is kind. BC11

LATINA LAY KNOWLEDGE SYSTEMS

Latina knowledge about breast cancer, its diagnosis and treatment, will be treated here independently of the social support system. Future analysis will incorporate the role of the social support system in the development of a Latina's lay knowledge about cancer.

Sources of Knowledge. One source of knowledge described was derived from having known someone with cancer or having heard about someone with cancer.

"Con mi mama fue cuando yo supe del cancer, el cancer del pecho... ella duró 4 años en cama con puro oxigeno...una vida artificial nada mas, si se la acababa el oxigeno le teníamos que dar masaje al corazón y soplarle en lo que llegaba el oxigeno" BC 21

With my mother was when I found out about cancer, cancer in the breast... she lasted 4 years in bed with only oxygen... an artificial life only, if the oxygen finished we had to massage her heart and blow until the oxygen would arrive. BC 21

Cancer as Communicable Disease. The meaning of cancer varies and there are individuals who believe cancer is contagious.

"...porque la palabra cáncer es como digo, yo, el SIDA...pienso. Pues el SIDA es una cosa de muerte también. Es una cosa que... se espanta cualquiera" BC19

... por que cuando mi hermana tuvo una experiencia muy dura, por que yo creo que mucha gente cree que eso es contagioso. Y a nosotros nos discriminaron mucho, una vez íbamos a una cenaduría, no nos quisieron vender, por que nos apuntaron muy mal. ¿Este como que no tienen posole, se esta moliendo la hoyo,” cuando nos dimos cuenta que no nos querían vender, nos dimos la vuelta, y dijeron a nuestras espaldas, “como les vamos a vender a esas cancerosas, no sea que nos vayan a contagiar!...Por eso yo les digo a mis hijos, que no quiero que nadie sepa, para que no me tengan miedo, asco” BC11

...My sister had a very different experience because a lot of people believed it was contagious. Many times we were discriminated. One time we went out to a restaurant where they did not want to serve us because people were pointing at us. “It seems like we don’t have anymore homony soup (posole).” When we realized that they did not want to serve us, we turned around and began to walk away. As we were leaving one person said, “Why are going to serve those cancerous people? What if we become contaminated!” That is why I tell my children that I do not want anyone to know. That way they won’t be afraid or be disgusted. BC 11

Lay Perceptions of Cause

Latinas interviewed to date present a variegated picture of knowledge. From the above section, the presence of a lump on the breast was recognized as a sign of a problem. Beyond that, there was a wide range of beliefs and knowledge regarding cancer.

Chemical Cause. One cause of their cancer was described to be “all the chemicals” used in America. One woman described past indiscriminate use of in the fields; as she stated, only recently has agricultural work involved a bit more concern about the welfare of the worker:

“... pues yo lo que pienso como, como dicen los mismos doctores, dicen que, que muchas cosas vienen por que químicas que echan en los, en las siembras pues. Para que se de la cosecha. Y si no hechan eso pues no se da, no se da nada. Ya esta como, ya ve que si uno anda en el fil y anda trabajando y echan fertilizante arriba los aviones. Tiene que salirse uno por que se pone llena de granos” BC6

...well I believe just like the way doctors do that many things come from the chemicals that they spray in the fields. They spray it so that there will be a harvest, otherwise there won’t be a harvest. It’s like when one is out there working in the fields and the airplanes spray fertilizers over you. You have to leave the field or you’ll end up getting rush. BC6

“Pues dicen que son las químicas, será? Tantas cosas que uno come, que todo tiene química. Antes...ya ve, tanta gente que se moría , “de que moría” sabe!. Y ahora pues todo eso, ahora todo, todo pues que de esto, de eso, de aquello. BC6

Well they say that it is because of the chemicals, is it? There are just so many things that one eats that has chemicals in it. Before, you know, there were a lot of people dying. “What they were dying of?... who knows!” And now, well all that, now everything, well all, of that, and this and that. BC 6

“Antes se levantaban las cosechas y nada de química ni nada, a ahora si no les echan químicas no hay nada, por que no se dan” BC6

Before the fields would harvest and there was no need for chemicals. Now if you don’t use chemicals, you won’t have any harvest. BC6

A physical blow. Other women attributed their cancer to a physical blow. One woman remembered that she often was hit in the chest when the grapevine she was twisting around posts would snap out of control. Another woman who had worked plucking

chickens as they passed by on a conveyor belt remembers stretching her arms out in front of her chest for long periods of time, causing her much pain. And according to one daughter, her father felt guilty because he had hit his wife in the past and wondered silently if this had caused the cancer. Other woman recalled having been kicked in the chest by a child throwing a tantrum or by a swinging door.

“He asked me, did I get hit. At any time in my age, did I get hit? I remember telling him, I don’t remember getting hit. But who knows, when you work out in the fields hard labor and you’re on the grapes. You might have, so I don’t know. Now I said, what if I did get hit? BC4

Racing Against Cancer How fast does a tumor grow? How much time does it take for a cancer cell to travel and spread? These questions haunted all the women. Some blamed medical professionals in general for their ineptitude in communicating, while others blamed the value of money, and still others felt that trouble at home distracted them.

“Llore, por que es una cosa que uno no espera. Es una cosa que a ti cuando te dicen, es cáncer y tenemos que hacer algo ya. Por que el cáncer crece en semanas, no es de esperar un mes o años. Entre mas pronto remuevan el... el cáncer es mucho mejor. Por que si uno espera semanas en que uno, piense en hacerse la cirugía eso crece de repente crece muy rápido” BC16

I cried, these are things you do not expect. Is like, when they tell you “is cancer, we have to do something soon!, because the cancer spreads en few weeks, is not like you can wait a month or years. The sooner the better, if they need to remove the cancer sooner is a lot better. You can not think for weeks if surgery is necessary or not, cancer grows very rapidly” BC16

“Hace unos años me hice el estudio pero no salió nada...pienso que fue en el 93 o 94 pero no salió nada...luego ya me empezó a doler el pecho, pero en ese tiempo cuando me hice el mamograma no salió nada... si, si, pedí el mamograma pero no salió nada y luego me deje, porque empecé a tener problemas con mi esposo y lo dejé a la desidia, asta que me volvió el dolor es cuando me decidí a ir al médico” BC21

A few years ago I did the breast exam but nothing came up... I think it was in 93 or 94 but nothing came up... then my chest began to hurt, but at that time when I did the mammogram nothing came up. yes, yes, I asked for a mammogram but nothing showed up and then I neglected myself, because I began to have problems with my husband and I left it ambiguously, until the pain came back is when I decided to go to the doctor. BC21

The race against cancer includes relatives living in Mexico who send herbs.

“Si yo este estoy tomando una yerba que me mandaron de alla de México...Ya ve como hay doctores que no creen e muchas cosas, como por ejemplo, cuando a un niño se le cae la mollera. Aquí no creen en eso, pero luego los lleva uno a sobar y se curan....El nopal con tomate de cascarrita y pepino. Le hacíamos un vasito, quedaba como horchata y ella comía mucho asado o así crudo. Una ensaladita y le quedaba el estomago bien fresco” BC11

And I’m drinking an herb that they sent me from over there in Mexico... And see how there are doctors who don’t believe in many things, for example, when a child “se le caé la moyera” (soft part of the head falls down). Here in the U.S. they don’t believe in that, but then we take them to a healer they get cured... the cactus with tomato (with peel) and cucumber. We would make her a little glass, it would look like horchata and she would eat a lot grilled or raw. A little salad a her stomach would be fine. BC 11

Never Enough Education Health information was sought. Some woman listened to radio talk shows, others watched community calendars on television and some were given information at child-care centers. Scant mention was made that they had received health information at church, though most did attend some sort of religious service. Information regarding government health programs was usually obtained not through a community center or a church but through the experience of a US-born relative or friend.

“Si pues yo decía “no, pues nosotros no sabíamos que se heredaba el cancer, hasta ahora que nos lo dijo la doctora, me dijo que alguna de mis hijas podían heredar el cáncer” pero yo le pido tanto a Dios que no...” BC21

Yes, well I would say, “no, well we didn’t know that cancer was hereditary, until today that the doctor told us, she told me that some of my daughters could inherit the cancer” but I ask God that it won’t...BC21

“No, no nada mas veía la televisión, los chequeos para el cáncer de la mujer y todo eso, pero no había folletos, ni cuando me hice el primer mamo grama... No, no! Ahora si donde quiera que voy tomo los folletos, donde me estan haciendo quimioterapia cada ves que veo folletos me los traigo para la casa” BC21

No, no I would only watch television, the check-ups for women’s cancer and all that, but there were no pamphlets, no even when I did my first mammogram...No, no! Now where ever I go I take the pamphlets, I always bring home the pamphlets from the place where I get chemotherapy. BC 21

Learning Learning was described as occurring in a variety of ways. One way occurred in the waiting room, when women waiting for their chemotherapy compared their diagnoses, their reactions to treatment, and their life experiences. It was most alarming when someone considered very ill would not be seen again.

“Por que de verdad que si a tratado con muchas personas que les ha pasado esta que así muy, muy como le dijera? Muy tristes. Allá tengo una amiga en Sinaloa también que le arrancaron un pecho” BC6

I have dealt with a lot of people that this has happened to them. It’s very sad. I have a friend in Sinaloa that had her breast removed. BC6

The power of understanding was described in a variety of phrases, including feeling “illuminated.”

“... pues por que nadie me alumbraba. Y ya ve que la gente por allá pues de donde yo soy nunca. Pues yo tengo mas de 30 años por acá pero a mi nadie me alumbraba, nadie me decía hazte esto, o eso, o nada” BC 6

...well no one would enlighten me on this matter. Well you know where I’m from, they didn’t. I’ve been here more than 30 years, but no one had enlightened me to tell me about this. BC 6

“... que alguien le dijera a usted esto, es esto. Esto, y eso... por que puedes tener esto, o eso. Eso es decir alumbrar, a decirle a aquella persona, te voy a decir esto. Eso le nombramos nosotros alumbrarle a la persona. Esto y esto, esas cosas. Mucha gente pues no sabe, verdad?” Por que? BC6

“That somebody would tell you that. Do this because you might have this. That is what I mean by illuminate when someone explains things to another person. That is what we call to illuminate, Or enlighten a person. BC6

Interaction with Physicians

With their knowledge base, the patients would seek care from a physician, the interaction below is described from their perspective and experience.

The Discovery The path most often described was to seek medical care once a breast abnormality was discovered. One group of women described practicing fairly regular breast self-exams and were clearly able to discern an abnormality when first observed. This leads us to suspect strongly that the observed delay in seeking medical attention might be attributed to difficulty in accessing health care, and in some instances to inaccurate communication rather than lack of interest or attention on the part of the participant.

“...ya me sentía el tumor. Y entonces yo le platique a mi hermana y a una cuñada... me dicen no te dejes, eso puede ser peligroso...como pueda ser, no pueda ser... Entonces estuve llamando a una y no me quisieron atender... cuando me dieron los análisis ya me sentí bien, por que me dijeron que no tenia nada...Yo y yo me espere hasta...y yo sentía como el tumor me estaba creciendo...el doctor me dijo que regresara hasta dentro de un año....Y fue cuando me reviso la doctora y me dijo...dice “aquí la revisaron hace una año?” le dije sí. “yo no la revise, verdad?” le dije no, fue un doctor. Dice “y porque si tenia el tumor ese como lo tiene, la dejaron asi? Yo no lo se! Y ya fue cuando me dijo... “la voy a mandar a que la vea el cirujano” que fue el que me opero. El doctor Saprás. Y cuando entre pues...me reviso luego, luego, empesó a mover la cabeza, y luego pues se dio cuenta. Estaba se sentía grande. Me tocaba yo así, y se sentía grande. Cuando me acostaba así, se quedaba así levantado, como...” BC2

...I felt the tumor. And I told my sister and my sister-in-law...they said not to let it go (unattended) because it could be dangerous...maybe yes, maybe no...I called and they (clinic) didn't want to attend to me...when they gave me the analysis they said that everything was fine that I didn't have anything...and I waited until I felt that the tumor had grown...the doctor told me to come back in a year. ...I went and when the (female) doctor examined me, she said,” did they examine you here a year ago?” I said yes; she asked, “I wasn't the one who examined you, was I?” I said no, it was a (male) doctor. BC2

“...No lo detectaban ellos, no pensaban que tenia yo eso, fíjese! Este yo cuando yo estaba en mi casa, año mas o menos, que yo me bañaba y me tallaba y decía “por que tengo sumido el pecho, por que tengo sumida la bolita? ¿por qué tengo así, y esta no? Me volví a bañar y lo mismo, pero yo a nadie le consultaba pues no me dolía nada, nada, nada. Hasta que mi nieta, “nana quiero que vallas para allá, por que ahí no ayudan a nadie. Pues yo soy una mujer sola, no tengo esposo, muy joven me dejó. Y este dice allá te van ayudar mira y no te va a costar. “Andale pues, pues vamos.” Y si pues, me hablaron de la clínica y mi nieta me dice “que saliste mal, que tienes cáncer. Lloré, lloré mucho..que me dijeran así, usted cree?” BC6

...They did not detected it, look! I did't think I had that. When I was in my house, about a year ago I was taking a shower, when I was scrubbing myself, I felt the lump. I asked myself what is this? and why is my nipple decompressed? Why do I have this one like this, but not the other? I took a shower and again I felt the same thing , I did not tell anybody, I did not consult with anybody. It was my granddaughter who said “Nana I want you to go to the other clinic, in that one, they do not help anybody”. I'm a single woman, I don't have a husband, he left me when I was very young...she said “in this one they will not charge you” I said Ok, lets go! Then they called me from the clinic, my granddaughter told me “they said you have cancer” I cried, I cried a lot... they just told me like that do you believe it? BC6

Communicating the Diagnosis. The circumstances of how and when the diagnosis of cancer was given to, varies with each woman. In most cases, the news of cancer was handled appropriately, though in some cases the news was blurted out by an insensitive health care provider.

One woman remembers hearing "cancer" as her physician chomped on her lunch, another woman was told of the diagnosis as she recovered from anesthesia after a biopsy. The Spanish-speaking nurse was surprised to know that the groggy woman had not been told.

"Dice, señora ya le dijeron que usted tiene cáncer? Le dije no, a mi no me han dicho nada. Pero no... todavía ni abría bien los ojos cuando me dijeron. Y luego después le dije yo aunque sea...imagínese como me sentí yo. De por si, con la anestesia me sentía, y ella decirme eso. Bien, bien que mal me sentí, muy mal. Y luego después le dije a mi cuñada cuando llegue aquí...dice como es que ella ti dijo eso? Le dije, eso me dijo. Dice, ella no tenía que verte dicho nada" BC 2 She said, "Ma'am did they tell you that you have cancer?" I told her no. "They haven't told me anything. But no...I hadn't even opened up my eyes well enough when they told me the news. Just imagine how I felt. As it is with the anesthesia and all and for her to tell me such news, I felt very bad. I then told my sister-in-law when I arrived here. "How is it possible that she could tell you that?" she said. She claims she shouldn't of told you the way she did. BC 2

In still another instance, a young family member was given the news of the diagnosis on the phone, and in her attempt to catch her grandmother before she left for work, yelled it out the door. As this woman lives in a small community, others also heard the news. This was reported to have a great impact on the young grandmother.

Some of the women interviewed believed they should have been given the news more sensitively. Many seemed to imply that their practitioners handled so many cases that theirs was just another breast with cancer. However, the few times a doctor took the time to question how the patient had arrived at the office, who was with the patient and how the patient was going to get home, this attention was appreciated even if it also alarmed the patient.

"I walked in there by myself. And he said, how are you doing?', fine I said. What about...Hey you live in Arvin,, don't you? I said yes. He said is your husband with you today. I said no he had to work. He said what about your son?' When he said that I looked at him and I said, doctor, you already told me what was going on. You are telling me it's positive. You are concerned about how I'm going to get home?... Yeah, he said I am sorry to tell you it is , and its stage is the size of a quarter and I would like to...."

While it appeared that some doctors wished to convey a matter-of-fact attitude toward the diagnosis of cancer, these rural immigrant woman felt desperation when they realized they had no insurance and no idea where to go for treatment. Does this suggest that what is so often called "fatalism" in Latino culture is in fact no more than fear of the limited options available to those without sufficient resources?

"Es un doctor Americano. Es un señor que yo pienso que es un gran medico pero es sumamente frio. Por que no es una persona que te pueda, no es una persona que te dice, todo va tener solución, Es muy frio...van y te dicen muy claro y sin rodeo... O me hubiese gustado

que hubiera sido mas, mas suave. Mas suave, quiero decir, me hubiera tratado de, a pesar de que a el no le llore, yo salí, cuando yo cerré la puerta de la consulta, yo vine llorando hasta el trabajo de mi esposo” BC15

Hi is an American doctor. I think he is a great doctor, but he is to cold. He is not the type of man that would say “everything has a solution” he is cold. He tells you as it is...I would like him to be more sensitive. I did not cry in his office, buy when I left and closed the door behind me, I started to cry, I cried all the way to my husband’s job. BC15

The Word “Cancer” A common experience described by the women was that not much else was heard after that terrible word “cancer.” We are probing to understand better the construct of the very word, “cancer”, and their reactions to hearing it.

To some women, “cancer” was such a powerful word that they preferred not to say it, but to refer to their diagnosis as “that illness.” BC6

“Si, se me hace muy pesado decir esa palabra, pues no se” BC 6

Yes, it is very difficult for me to say that word (cancer). BC 6

Yet others felt that science had advanced and that doctors were trying different ways to beat cancer, even giving chemotherapy before surgery to kill the cells:

“El cancer...cuando ud. escucha esa palabra, luego, luego piensa el cancer no tiene cura. No han allado nada para curarlo verdad? o sea lo mantienen, como ahorita con estos tratamientos de quimioterapia, dice el doctor que es muy bueno por que antes no lo hacían asta después de la operación, pero ahora es mejor hacerlo para ir matandole la celula. Esto se hace para asegurarse que todo este bien, se siente uno mal como por diez días, pero luego sigue uno contento” BC11

Cancer...when you hear that word, right away you think that cancer has no cure. There isn’t a cure for cancer, right? What I mean is you manage it. Like right now with the treatments and chemotherapy that I’m going through. The doctor says that it is very good because before you didn’t go through (treatments) it until after the operation. Now it is best to do it so you can begin to kill the cells. BC11

Incomplete concepts Examples of how relevant concepts were incompletely communicated by medical personnel abound in the Spanish interviews.

“...poco tiempo te voy a quitar la otra. Que me las quiten, con eso y sin eso voy a vivir. Aquí conocí a una mujer le faltaron las dos. Luego, luego le arrancaron la otra, una americana. Le dicen que por el cigarro, que por eso. Yo nunca fumé, nunca tomé yo nunca..nada!” BC6

“...in a short period of time, I will take out the other one (breast).” Take them away, you know with or without them, I will live. Here I met a woman who was missing both. Right away they removed them, it was an [Anglo] American woman. They tell her it was because she smoked. That was why she had it. I never smoked, never drank, I never did any of that...nothing!” BC6

The loss of hair through chemotherapy was always told to be expected, yet the explanation of how the chemotherapy actually causes hair loss went unanswered.

Most alarming and worthy of further inquiry was that to some, breast cancer public service announcements on television or radio were at times confusing and too many times

so frightening that they actually caused inaction. After some probing, it became apparent that many participants misunderstood risk factors as conditions of preventing breast cancer.

“...yo nunca creí cuando me dijo el doctor que era cáncer. Le dije que yo no tenía cáncer, que no era cáncer... si, es que ella pensaba que como, pues no como yo de pecho tengo, por ejemplo las personas que no dan pecho y no mas usan la leche de polvo. Entonces quiere decir que esas tienen mas riesgos. Y como ella que dio pecho tiene menos posibilidades” BC 9

...I never believed the doctor when he told me it was cancer. I told him that I didn't have cancer, that it wasn't cancer. Well I believed that only those who used powdered milk got it because you know I had breast fed. So then that means that they are at higher risk. And since I had breast fed, there were less risks. BC 9

One commercial, which depicts cancer as a lover of women—to the point of death—created anxiety, especially in women who practiced healthy habits precisely for fear of getting ill since they did not have the health insurance necessary to pursue a negative diagnosis. Others felt that doctors must have gotten confused or else caused death.

“...esa señora era mi amiga, pero el doctor se confundió y no lo operó todo. Desde un principio debió haber cortado todo el pecho, porque ya lo tenía muy regado...” BC20

... that lady was my friend, but the doctor was confused and didn't operate it all. From the beginning he should have cut the entire breast, because she had it really spread...BC20

“...Yo tengo miedo por que ahí a donde yo voy, una señora se murió, no la operaron bien y tan mal lo hicieron que se murió. No duró ni siquiera 6 meses...” BC20

... I am scared because there where I go, a lady died, they didn't operate her properly and they did it so bad that she died. She didn't even last six months...BC 20

Understanding Chemotherapy Many women shared that they had had very little knowledge about chemotherapy and radiation. Many explained how confusing chemotherapy was and some still wonder how chemotherapy works.

“No, a mi no me explicaron nada. Nada me dijeron. Yo cuando iba, cuando me dijeron que si quería que me la dieran, pues les dije que si es necesario si. Pero yo nunca pensé que fuera a tener esa reacción. Y cuando yo fui yo tenía mi pelo bien largo, hasta acá...” BC2

No, they did not explain anything to me. They did not tell me anything. When I would go and they would ask if they wanted to give it to me, well I would say yes, if it's necessary. But I never thought it would have that reaction. When I went I had my hair real long, down to here. BC 2

“...si es un liquido que me lo ponían aquí en esa vena..me inyectaban dos líquidos. Eran unas jeringas asi. Una roja que es la que me tumbo el cabello como kool-aid. Y la otra como era amarilla. Y me ponían una bolsita aquí asi, un pa los vómitos. Y una de suero...sentía como que se me turbaba la nariz...yo nunca pregunte? De que lo hace? ...Uno miraba los líquidos y decía pues, me imaginaba yo que, De que era esto, que es tan fuerte. De que, de donde? No, nunca me podía explicar yo” BC 19

...it was a liquid, they put it in my vein...they injected my two kinds of liquids. The syringes were about this big. The red one, like cool-aid is the one that made me loose all my hair, it bother my nose, but I never asked why. I used to look up the liquids and wonder, what they were made out of, why they were so strong? I couldn't never explain myself.

*“Por que me decían algunas mujeres ahí que algunas no se lo hacían, por que no lo soportaban. No soportaban la terapia. Yo miraba que a unas, les hacia muy fuerte, yo pienso que que estas se encontraban muy mal, para que les hiciera así. Y yo decía “a mi no me ponen esto tan fuerte, a mi no me hacen esto, y por que a ella?...” entonces me decían ellas que, le decían a mi nieta, que ellas ya estaban muy avanzadas. Les ponían ese tratamiento para... me toco ver a una Japonecita como tres veces o cuatro como a las dos...”*BC 6

“Because some women there would tell me that they wouldn’t do it, because they couldn’t handle it. They couldn’t stand the therapy. I saw that some were hit hard, I think that these were really sick of it, affected them like that. And I would say... “they’re not going to put that so strong, they won’t do that to me, and why to her?...” and then they would tell me that, they would tell my granddaughter, that they were really advanced. They would do that treatment for... I had a chance to see a Japanese lady like three times or four how they both...” BC 6

MEDICAL SYSTEM INTERACTIONS

A good part of the participants’ experience was their interaction with the medical care delivery system. The social support system is involved in the interaction, but for the present purposes of conceptualizing, the medical care system will be treated independently of the social support system.

Medi-Cal Bureaucracy Some women described the difficulty of obtaining assistance from the county. Participants described negative experiences in county offices from lack of privacy—being interviewed about personal matters in a open stall—or from lack of sympathy—being told Medi-cal was being denied because a diagnosis of cancer was not an “emergency.” When some women questioned the denial of assistance, they were told that the only solution was to “appeal” the decision. Appealing a decision meant more paperwork.

“You had to take all your stuff down every time you wanted to go in there. You had to take all your receipts for this, your...the amount of money you had made, the this and that, uh that she used to have to get a slip signed from me that she was paying half the rent and stuff, I mean everything you know. And they would set down and tell her whether she qualified or not. Ad if she did...then they’d give you that referral.. .they’d giver her a 30 day referral within that 30 days you could use it. But after 30 days, you no longer qualified if something else happened you had to go through the whole dog on thing again. You’d qualify for the whole month, but ever time you a doctor’s appointment was not in that month, you’d had to go in there and get a referral first before you go to the doctor. ...most of the ladies were decent....but this one guy...he acted as if he was just a little bit better than anybody else. He’d just, you know well uh, you’re a nobody and here I am in a good position so I can, you know I’m God, you do what I say or else. ...she hated to go in there and talk to him. In fact, if she knew she had to talk to him she probably wouldn’t go in” BC7

“Apenas apliqué en Enero, antes sí teníamos medical pero nos lo quitaron porque el trabajaba y ganaba mas del límite. Pero como ahora ya no esta con nosotros y yo gano poquito...no salgo a trabajar sino que hago algo aquí en la casa...” BC21

I barely applied in January, we had medi-cal before but they took it away because he worked and earned more than the limit. But since he is no longer with us and I earn very little... I don’t go out to work but instead I do things here at home... BC21

“...adelante me dijo...”yo te voy a ayudar a salir adelante y vera que te vas a poner bien”, y hasta ahorita pues si, yo me siento bien pero aún estoy con los efectos de la ultima quimioterapia, y pienso darle las gracias por que si me ayudo bien...” BC21

... ahead she told me... "I will help you get ahead and you will see that you will be fine", and until now, yes, I feel great but I still feel the effects of the last chemotherapy, and I am thinking of thanking her because she did help me a lot... BC21

Follow up treatment

"No mas que el tratamiento que ella tiene pues es...tomar pastillas por cinco años. Entonces eso es para que...como lo dice ella, creía que tenía todavía cáncer. Le digo "no, no es por que lo tengas, es para que si tiene alguna célula que este viva o algo se muera con la pastilla". Es lo que yo pienso que será para eso el tratamiento y luego pues esta el chequeo que va cada tres meses cada cuatro meses a chequearse al doctor" BC 6

But the treatment she has is well... take pills for five years. Then that is for how does she say is, she thought she still had cancer. I say, "no, that's not why you have it, its just in case you have a living cell or something, it will die with the pill." That's what I think, that is what the treatment is for and then, well there is the check up that occurs every three months, every four months to get checked by the doctor.

The Angel With No Name - The Breast Cancer Treatment Fund All women, regardless of formal education and level of medical insurance, knew that an abnormal finding in the breast meant the need to pursue professional help. Many did not know the name of the fund that provided coverage for treatment—the Breast Cancer Treatment Fund. Some credited the assistance they were given to the American Cancer Society. Only one of 15 immigrant women actually mentioned having been visited by someone from the American Cancer Society. Most women were referred for assistance by office personnel or by a friend who knew a friend who then found help for the woman. One woman thought it was a type of government health insurance.

"No pues me ayudo el gobierno, pero ella las aseguranzas y todo. Ella hablaba para un parte y para otra. Aquí cuando la primera clínica, la que esta aquí, la chiquita esta aquí cerquita. Ellas me consiguieron una aseguranza, y esa aseguranza me pago todo. Ya ahorita ya se me acabo y ahora pues tengo que agarrar a ver otra" BC6

No but the government helped me, but her the insurances and everything. She called one place and another. Here in the first clinic, the one that's here, the small one is close to here. They were able to get me an insurance, and that insurance paid for everything. Now, it finished and now, well I have to get another one. BC 6

IMPORTANT NOTATION: In 1972, DDT, a pesticide commonly used on California agricultural fields, was cancelled by EPA administration. DDT is a pesticide absorbed and stored in fat cells. If women worked in the fields prior to 1972, there is a good chance that she was exposed to DDT. All rural immigrant women interviewed have worked in agriculture and/or lived in agricultural land. It is important to research further the possibility that a higher-than-normal rate of breast cancer might exist among this population of immigrant rural women aged 40 to 80. It was not uncommon for immigrant women to work in the fields as young as 12 years of age. Looking at ten year cohorts of women age 40 to 80, a woman now 80, if still alive, would have worked in the fields 40 years; a woman now 70 would have worked in the fields 30 years; a woman age 60 would have worked 20 years; a woman age 50 would have worked in the fields 10 years before DDT was "cancelled" or pulled from use.

(6) KEY RESEARCH ACCOMPLISHMENTS

As only Year I of this project has been completed, this section is not yet applicable.

(7) REPORTABLE OUTCOMES

As only Year I of this project has been completed, this section is not yet applicable.

(8) CONCLUSIONS

The following conclusions are derived primarily from the partial analysis of two cell – Immigrant rural women and US rural women and they are derived only from one perspective – the perspective of the affected woman.

Conclusion I

A Latina woman's knowledge, attitude and behavior towards breast cancer are influenced by the quality of the communication afforded her by the various components of the health care system. The health care system is complicated, and access is dependent upon a variety of factors beyond the fact of insurance coverage.

The breast cancer experience has four phases: Phase I the discovery of an abnormality; Phase II the diagnosis; Phase III the treatment; and Phase IV the sequel.

A woman's psychosocial support system functions at each phase to intervene, negotiate, supplement and extend services and information, wherever our complicated medical care system has failed. In essence, the support system helps the patient "connect the dots" of a disjointed services delivery system.

The exploration of a woman's recollection and perception of the breast cancer experience has surfaced dimensions of healing that reveal a wide range of communication and cultural disparities.

A clear understanding of these disparities how a woman's psychosocial support system has stepped in to glue and connect the dots allows us to understand where the glue was needed and how we can better educate and familiarize our medical professional staff with Latina women who have been diagnosed with cancer.

Training of those who serve as interpreters (whether they be employees of a clinic or family members) so that how they can better manage the communication will be key to allowing a Spanish dominant woman's to better understand and manage breast cancer.

Three patterns of behavior by interpreters have influenced a woman's comprehension of the diagnosis and treatment:

1. Short cuts taken by interpreter to expedite the visit;
2. An interpreter's own emotional reactions to the situation;

3. Inaction by an interpreter to request clarification of concepts that are complicated and confusing to the interpreter.

Conclusion II

The one consistent individual in these women's lives, the spouse/partner has for the most part been neglected by the medical world. He has many questions and needs much guidance to be able to understand and deal with the realities of cancer. It is not primarily the lack of a breast that is a problem, but the fear of a losing the normal everyday activities of that individual who is responsible for creating "family" so important for Latinos.

(9) REFERENCES

As only Year I of this project has been completed, this section is not yet applicable.

(10) APPENDICES

As only Year I of this project has been completed, this section is not yet applicable.